STATEMENT FOR THE RECORD

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"Advocating for Answers: Health Care and Research Needs
that Support Individuals with Long COVID-19"

Submitted by Survivor Corps

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Chairwoman Eshoo, Ranking Member Guthrie, Chairman Pallone, Ranking Member McMorris-Rodgers, and distinguished members of the Subcommittee:

Thank you for the opportunity to submit testimony today. Providing a voice to those suffering from Long COVID-19 is an essential first step in addressing the abundance of new and challenging issues facing the medical and research communities who seek to work with patients to find successful health care strategies to address the Post-Acute Sequelae of SARS-CoV-2 infection ("PASC"), sometimes referred as "long hauler's syndrome."

Survivor Corps is the largest grassroots movement in America dedicated to actively ending the COVID pandemic. With over 165,000 members we are continually connecting, supporting, educating and motivating those affected by COVID-19, including colleagues, families and friends. We aim to mobilize as many as possible to support all ongoing scientific, medical and academic research. As we look to the second year of this pandemic, our mission includes:

- Supporting COVID-19 survivors in their recovery from acute and long COVID;
- Assisting with the advancement of research, data collection and analysis, and the development of health care practices;
- Encouraging government backed interventions such as coordinated care, improved access, the launch of registries and the development of benefit programs providing insurance, disability and financial assistance;

- Bringing patient voices to the forefront of scientific research, thereby redefining citizen science so that citizens and scientists work in collaboration to honor the needs of patients and accelerate the pace of scientific discovery; and,
- Memorializing the national reaction to COVID in order to maintain a record of best practices to help ensure that an equitable plan is developed to better prepare us for pandemic challenges we may face in the future.

As of April 27, 2021, SARS-CoV-2 has infected more than 148 million people worldwide, with over 32 million cases and 569,000 deaths occurring in the United States. Some states still struggle with double-digit positivity rates and caseloads equal to or greater than those experienced in October 2020. The acute manifestations of this devastating pandemic have taken lives, disabled our economy, and disrupted our communities. However, the long-term sequelae of infection may be just as daunting, with implications for massive numbers of people left with chronic conditions totaling in the millions. Initial studies suggest that anywhere from 30 to 60% of people infected with SARS-CoV-2 exhibit mild to disabling long-term symptoms.[1,2] Many studies indicate that PASC can involve multiple organ systems[3], spanning the range of fatigue, tachycardia, memory problems, difficulty concentrating, blurry vision, and severe headaches, among more than 100 symptoms. The medical specialists who are involved with care of people suffering from PASC include cardiologists, pulmonologists, endocrinologists, neurologists, nephrologists, gastroenterologists, radiologists, dermatologists, psychiatrists, pain specialists, rehabilitation specialists, general practitioners and specialists from other disciplines.

The need for a multi-disciplinary care for PASC patients has been shown in numerous research studies. Survivor Corps surveyed 5,163 COVID-19 survivors reporting symptoms more than 21 days following SARS-CoV-2 infection.[4] Participants reported an average of 21.4 symptoms and the number of symptoms ranged from 1 to 93. The most common symptoms were fatigue (79.0%), headache (55.3%), shortness of breath (55.3%), difficulty concentrating (53.6%), cough (49.0%), changed sense of taste (44.9%), diarrhea (43.9%), and muscle or body aches (43.5%). The timing of symptom onset varied and was best described as happening in waves. The longest lasting symptoms on average for all participants (in days) were "frequently changing" symptoms (112.0), inability to exercise (106.5), fatigue (101.7), difficulty concentrating (101.1), memory problems (100.8), sadness (99.2), hormone imbalance (99.1), and shortness of breath (96.9). Many symptoms presented with pain. These symptoms can be severe enough to make it difficult or impossible for many people to return to work or perform necessary, everyday activities without assistance.

Additional studies building on Survivor Corps' findings have been and are being carried out. One study looked at electronic data sets and reported symptoms experienced by those with PASC.[5] Twenty-seven percent of subjects reported persistent symptoms after 60 days. Presenting symptoms included palpitations, chronic rhinitis, dysgeusia, chills, insomnia, hyperhidrosis, anxiety, sore throat, and headache. Of great concern was the finding that roughly 32% of those reporting symptoms at day 61+ were initially asymptomatic at the time of SARS-CoV-2 testing. The public health implications of PASC infection are vast. At this time there are no guidelines for diagnosis, case management, assessment or

[1] https://jamanetwork.com/journals/jama/fullarticle/2771581
[2] https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2776560
[3] https://bmjopen.bmj.com/content/11/3/e048391
[4] https://www.medrxiv.org/content/10.1101/2021.03.22.21254026v1
[5] https://www.medrxiv.org/content/10.1101/2021.03.03.21252086v1

care. Additional studies are urgently needed that focus on the physical, mental, and emotional impact of long-term COVID-19 survivors who suffer from PASC infection.

For the millions experiencing long-term symptoms, there needs to be a home in the government for information regarding their condition and care. This central office must be tasked with driving and coordinating scientific information and research, distilling information about clinical patient experiences, developing guidance to the medical community on best clinical practices, advancing policies, and supporting the people's interests. We advise that patient-centered, social scientific research be supported on equal footing with clinical studies of PASC. PASC causes a wide range of sequelae and each individual's experience with the disease can vary to an extraordinary degree. Because of this, a true understanding of PASC can only be developed by conducting research that can characterize the patterns of experiences and health impacts of diverse groups of people suffering from PASC and using these findings to create hypotheses that guide clinical and translational research. Just as good clinical research is the pathway to understanding the biological underpinnings of PASC, nationally funded, social scientific research is essential for understanding what clinical research and which federal policies will best enable PASC survivors to recover and return to work and daily activities.

Government leadership is essential to prevent an American crisis caused by COVID's unique long-term pathology. Presently, there is no coordinating entity taking charge of collecting data on all people suffering from PASC, developing practices in the health care field, and leading the development of solutions from prevention to treatment to recovery. The NIH has issued a call for research and identified the most pressing research questions related to PASC and Congress has earmarked $1.15 billion in funding over four years to support this work. This is a good first step, but more support for research is needed. In addition, financial support is essential for those with PASC infection who now struggle with the high cost of healthcare, therapeutics and medical testing, as well as increased debt, loss of employment, and housing and food insecurity. Additional funding also is needed to support patient-centered stakeholder research that assesses the physical, mental, occupational, and social impacts of PASC, as well as research to develop diagnostic and therapeutic tools, medical and nutritional interventions, mental health support programs, and work policies that address these impacts. Industries in the health and recovery fields, from insurance to fitness to rehabilitation, are floundering without leadership as they seek to plan how to serve affected individuals best and move forward in a post-COVID economy.

Many governmental departments have launched programs and efforts on COVID-19 recovery. These programs exist in offices in the Department of Defense, Veterans Affairs, Labor, Social Security and Education, and Health and Human Services, including the FDA, NIH, CDC, ONC, AHRQ, CMS, and HRSA. Still, to be most effective, they require coordination. The wealth of information on PASC grows daily, but it does not currently have a home base from which it can be used for prevention, intervention, and guiding policy. We urge Congress to find a home from which information can be captured and disseminated to the medical and research communities and to the general public, and from which a roadmap to recovery for individuals who suffer from the condition can be designed and implemented.

Leadership is needed to promote partnerships and convene discussions between medical societies, patient advocacy groups, research institutions, international coalitions, and policymakers. As other Departments and Agencies focus on vaccinations, acute treatments, opening the economy, school re-opening, and other aspects of the pandemic, efforts must be led that address the needs of people whose experience with the illness has not ended.

The list of to-dos in the arena of PASC ranges from the basic to the complex, including refining the definition of the condition so that the medical and insurance industries can coordinate care and monitor recovery. Multidisciplinary Post-COVID Care Centers need to be established nationally, with uniform standards, coordinated intake, screening, care and monitoring strategies. In addition, at-home patient care recommendations need to be developed to assist those who do not yet have access to these centers, or who experience economic or healthcare insecurity. These centers could establish a 'gold standard' of care, bringing together new technologies that would elevate America's healthcare strategies, as we adopt holistic, transparent and more efficient systems. In the absence of this, millions of Americans will compete for scarce openings at expensive care centers that will have different approaches for PASC, amplifying health care inequalities, and bolstering health disparities that leave the most disadvantaged groups behind. Systematically monitoring the effectiveness of PASC care strategies will help set a standard for post-pandemic management in preparation for future health disasters.

PASC's impact on disability and workforce policies are also in great need of attention. Without significant investment today in diagnosis, treatment and health management strategies, COVID-19's long-term economic impact will go unchecked. Not since World War II has America faced the challenge of supporting such a potentially large chronically disabled population in need of care. Only economic investment today can protect our national workforce and economy tomorrow.

PASC needs a champion and a home where it will not be lost amid decades-long analyses. Americans need a coordinated movement that brings together patients, re-builds trust in the government's ability to care for its citizens, coordinates the efforts of medical scientists, public health workers, and policy makers, and helps to fast-track a pathway to recovery for the tens of millions of Americans who have survived COVID-19 and suffer from its aftermath. We urge Congress and the Administration to:

1. Champion this effort,
2. Require and support leadership and coordination between individuals, organizations and agencies working on these issues, and
3. Adequately fund all of the efforts and entities mentioned above.

Thank you, Madame Chair and members of the Subcommittee. We appreciate the opportunity to address the personal, public health, economic and societal problems brought about by long COVID. Leadership, planning and coordination of efforts are desperately needed as we learn more about PASC infection. How America responds today will define who we are in the decades to come and will prepare us to respond more effectively to health care crises we may face in the future.

We look forward to working collaboratively to address both the immediate challenges of this pandemic and the challenges associated with long COVID conditions. Thank you for the opportunity to submit this testimony today.